Parliamentary and Health Service Ombudsman

End-of-life care: improving 'do not attempt CPR' conversations for everyone

Since publishing this report, we have changed our name to the **Public Service Ombudsman**.

Our role and the service we provide remain the same.

Public Service Ombudsman

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About us

We are the Parliamentary and Health Service Ombudsman.

We independently investigate complaints about UK Government departments and the NHS in England. Our service is completely free, focused on fairness and open to everyone.

We champion higher standards of behaviour to help inspire a better relationship between people and public services.

We work closely with people to understand where, how and why public services sometimes fall short and fail to put people first. And then we find ways to put it right. This can involve explanations, apologies and taking steps to learn and improve.

We believe in the power of complaining to bring lasting change. We share findings from our casework more widely to help improve public services and complaint handling for everyone. This can include presenting reports to Parliament so it can make sure organisations act on our recommendations.

Acknowledgements

Thank you to everyone who gave their time, expertise and guidance to support the development of this report and its recommendations.

This includes the Royal College of GPs, the Royal College of Physicians, British Geriatrics Society, The Society of Acute Medicine, Care Quality Commission, General Medical Council, Health Services Safety Investigations Body, Patient Safety Association, the Nursing and Midwifery Council, LeDER project, Resus Council, Learning Disability England, Disability Rights UK, British Institute of Human Rights, Equality and Human Rights Commission, Compassion in Dying and NHS England (learning disability network leads, Dignity and Ethics team and Digitisation teams).

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Thank you also to the nurses who attended our focus groups and interviews, and the doctors who filled in our survey. We do not underestimate the time given under current pressures on the NHS, and this showed the desire to see change to the current system.

Foreword from the Ombudsman

End-of-life care provision is some of the best service the NHS has to offer. It is associated with an empathy-led, personalised approach at the heart of palliative practice.

Conversations about end-of-life care are sensitive and emotionally challenging. They need to be conducted by professionals who have had appropriate training, in partnership with patients and their families and supporters. The aim is to help them make the right decision, properly informed and at the right time. However, the evidence of this report shows that good practice is missing in some parts of our healthcare system, and that this can have profoundly traumatic consequences for patients and their families.

When the COVID-19 pandemic hit, it pushed many doctors, patients, families and carers to make end-of-life decisions in pressured and emotionally charged environments, often at a distance from affected relatives. These are not ideal healthcare settings for thorough, supportive and inclusive conversations to take place.

Perhaps unsurprisingly, we received many complaints about Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) conversations during the pandemic, especially from or on behalf of disabled people and older people. Like many facets of the pandemic, this exposed issues that had been lying dormant in the health service for some time and have continued post-pandemic.

This report delves into the systemic reasons for failure and the inequitable impact this has on disabled people and older people. I am immensely grateful to all of the healthcare staff, people with learning disabilities, older people, regulators, member-led organisations, charities and researchers who gave their time and expertise to help us understand this further.

Viewing the rights of older people and disabled people together makes sure that supported, personalised decision-making takes precedence, rather than an imposed or guardianship model. This approach is integral to this report. Disabled people and older people can be marginalised as a result of a perceived heavier reliance on the support of others, and we know this manifests itself in health and social care systems.

I was struck by a quote from one person we spoke to: “You’re born with a learning disability, but you don’t die from it”. It is particularly important for older people and disabled people that care and consideration is given to end-of-life conversations, to avoid any perceptions that bias has affected decision-making. In one case we upheld, the patient had ‘learning disability’ written as one of the reasons for their DNACPR notice. This clearly does not meet the FREDA principles of fairness, respect, equality, dignity and autonomy in healthcare (‘Care Quality Commission, ‘The importance of human rights in our approach’).

Having conversations about DNACPR is a legal requirement. Failing to do so constitutes maladministration and a breach of human rights. Time pressures or concerns of distress could be reasons for delay, but the conversation will still need to take place. A rights-respecting, interactive conversation on how someone wishes to end their life is a basic part of end-of-life care provision.

The COVID-19 pandemic was both a trauma and a national test. Now we have a chance to learn from the mistakes that exposed flaws in the system. Healthcare staff have told us they want help to make this happen around DNACPR conversations. I hope this report is a key step in making sure the health service supports them to do so.

Rob Behrens CBE

Parliamentary and Health Service Ombudsman

Executive summary

Why we have written this report

During the COVID-19 pandemic we received a higher number of complaints than normal about communication of 'do not attempt cardiopulmonary resuscitation' (DNACPR) decisions.

Our casework and further research have shown that while the pandemic highlighted problems with DNACPR conversations, as with many other issues, the problem is not restricted to that time.

Flaws have been exposed in the end-of-life care system, showing that:

- advance care conversations are not taking place in the ideal setting for patients or healthcare staff
- healthcare staff are not being trained with all the skills needed to have these conversations
- patients and their families and carers are not always getting the right support to have a balanced discussion that respects their rights as individuals.

Almost all of the DNACPR complaints brought to us were from or on behalf of disabled people or older people. These are also the groups of people who were most affected by COVID-19 as a virus (Office for National Statistics, 'Coronavirus (COVID-19) related deaths by disability status, England and Wales: 2 March to July 2020'). These included a case we upheld, where the reason given for the DNACPR was the person's learning disability and mental health condition.

Our casework also told us that:

- patients and their families and carers were consistently not involved in DNACPR decisions during the pandemic and healthcare professionals failed to communicate with them
- records were not checked for existing DNACPR decisions
- DNACPR records did not follow patients to different health settings
- patients were not getting support for a range of communication needs.

We found evidence in our casework of the same themes coming up before and after the pandemic.

Our casework evidence raises serious questions about the quality of communication and whether a human rights-led approach is being taken to patients' care.

What we did

To help answer these questions, we commissioned the British Institute of Human Rights (BIHR) and Compassion in Dying to carry out additional independent research. We wanted to work with people with learning disabilities and older people to inform our research and recommendations.

We also carried out a survey of doctors in England to understand their views, and held focus groups and interviews with nurses working across learning disability, geriatric and palliative care.

We combined the output from this work with our casework findings to create the evidence base for this report.

What we found

Our main findings are:

1. People are not told as a matter of course (as is legally required) that a DNACPR decision has been made. This causes distress and affects people's trust in the NHS and doctors.

2. Conversations about end-of-life are often held too late. Acute settings and A&E are not the best places for sensitive and thorough conversations, but this is where most conversations happen. Simple changes to common practice in the health service could support these conversations taking place before emergency settings.

3. When DNACPR decisions are left too late, it often leaves conversations to the patient's family, leaving the patient out of the conversation entirely. This causes distress to families or carers and can leave people with a sense of injustice, leading to complaints to us.

4. There is a lack of accessible information given at the time or before DNACPR conversations take place.

5. There are issues with record-keeping and documenting decisions. Correct and up-to-date DNACPR decisions do not follow a patient throughout the medical system. While a DNACPR decision should be logged on patient records, this cannot be accessed across the whole health system and there are often problems with advance decisions being logged, updated and respected. There is also not enough space on most forms to accurately record conversations.

6. People voiced genuine fears about ageist and ableist attitudes and behaviours in the NHS.

7. The general public are often unaware of who is responsible for making a DNACPR decision and what treatment it covers. This leads to frustration and distress when people believe it is their decision and not a clinical decision.

Our evidence suggests that in addition to lack of time, inhibitions in wider society to talking about death and dying can mean that conversations about DNACPR happen later in care and often in emergency settings.

The NHS describes a good death as "the best death that can be achieved in the context of the individual's clinical diagnosis and symptoms, as well as the specific social, cultural and spiritual circumstances, taking into consideration patient and carer wishes and professional expertise" (NHS England, 'What is a good death?'). Changing our perceptions of end-of-life care is linked to the way we view those with less power and their right to have a 'good death'.

The principles seen in best practice around end-of-life care, including empathy, good communication, time for human connection and personalised care, are examples of the best the health service has to offer. We have consistently spoken to doctors and healthcare staff working in challenging environments, continuing to make sure people die with dignity, respect and kindness.

We believe that if the principles often shown in end-of-life care settings were replicated in all settings where patients may reach the end of their lives, this would improve the fundamental aspects of healthcare.

What needs to happen next

Our recommendations are designed to make sure the NHS enables empathetic and thorough conversations that respect individuals' rights, and that staff are supported to do this.

Recommendations have been informed by all of the contributors to this report.

1. Training:

    - All CPR training for all doctors and nurses should include scenario-based training on DNACPR (aimed at all NHS-funded providers). This part of the training should be co-designed with older people and disabled people.

2. Communication:

    - Integrated Care Boards (ICBs) should make sure that accessible communication materials, which meet the needs of their population, can be accessed through health settings to support staff, patients, families and carers when having DNACPR conversations.

    - The Royal College of GPs, the Royal College of Physicians and the Royal College of Nursing should develop guidance for GPs, physicians and nurses working in acute care, to promote earlier conversations with patients,

families and carers about wishes at the end of life and about advance care planning.

- NHS England and ICBs should expand the number and type of staff who can formally support DNACPR conversations in multiple settings. This should include nursing staff, acute liaison nurses, local advocacy services and learning disability nurses. NHS England and ICBs should also recognise the importance of families and carers in supporting these conversations.

3. Regulation:

   - The Care Quality Commission (CQC) should update cross-sector guidance underpinning regulations to include planning for health inequalities in end-of-life care.

   - The CQC should make sure that assessment of providers' compliance with standards of good practice around DNACPR is strengthened in its regulation of all services, with a particular focus on improvement in secondary care services.

4. Record-keeping:

   - NHS England should make sure, for advance care planning conversations, the primary care electronic patient record (EPR) is the single place for holding end-of-life care plans and DNACPR records. This should feed into the multidisciplinary shared care record and be accessible across all health settings. This needs to enable immediate digital access across all NHS provider organisations for healthcare staff and patients. Improving the interoperability of patient records would have far-ranging benefits beyond end-of-life care planning and achieving a single shared care record should be the ambition as soon as is practically possible.

   - NHS England, ICBs and trusts should make sure DNACPR decision-making tools include clear guidance on legal duties for doctors.

   - NHS England and healthcare providers should make sure there is more space to document conversations and decisions on DNACPR decision-making forms.

5. Overarching recommendation:

   - We call for all outstanding recommendations in CQC's 'Protect, respect, connect – decisions about living and dying well during COVID-19' to be implemented.

Our commitment

We will train all Ombudsman staff on disability awareness in our 2024 to 2025 Active Inclusion learning programme, including learning disability and neurodiversity. This should mean staff will be able to recognise when these characteristics arise as a factor in a complaint and better understand the lived experiences of individuals and families. We will continue to progress work to make our services more accessible to disabled people, older adults and people affected by issues in this report.

Introduction

Why we have written this report

During the COVID-19 pandemic we received more complaints about DNACPR notices than we had previously. The number of complaints upheld increased from single figures each year to double figures during the pandemic.

Complaints we received during this time highlighted issues in applying DNACPR notices and communicating about them.

Almost all of the complaints were from or on behalf of disabled people or older people, who were most affected by COVID-19. This raised questions about the effectiveness of communication with these groups, particularly during a national crisis when people using the NHS could not have their usual advocates and carers with them. The government has since recognised the impact of visitation restrictions and changed the law to allow visitation as part of care in future crises (Department of Health and Social Care, 'Government to legally make visiting a part of care').

Although issues involving DNACPR notices were worsened and highlighted by the pressures of COVID-19, they were not confined to the pandemic. Our casework evidence and research show that some of the same issues were present before that time and are still prevalent. We wanted to understand what is causing these consistent failings, particularly for disabled people and older people.

Due to the attention brought to the issue of blanket DNACPR decisions without consultation, the CQC published a substantive report in March 2021 ('Protect, respect, connect – decisions about living and dying well during COVID-19') and the Ministerial Oversight Group (MOG) on Do Not Attempt Cardiopulmonary Resuscitation decisions was created as an outcome to develop and implement policy changes. The CQC report and the MOG developed recommendations to make sure incidents like those at the start of the pandemic never happened again.

The MOG has not met since May 2022 (Department of Health and Social Care, '17 May Summary note of meeting'). This has left an accountability gap, as the organisations responsible for implementing recommendations are no longer reporting on progress.

This report builds on previous work by the CQC, with the British Institute of Human Rights (BIHR) and Compassion in Dying. Organisations responsible for patient safety and advocacy, such as the Health Services Safety Investigations Body (HSSIB), have also recently produced reports and recommendations on caring for adults with a learning disability in hospital. A lack of practical changes and a failure to embed recommendations in the health service are still areas for concern, particularly where culture prevents change and poor practice continues.

As we learn from the experiences of the COVID-19 pandemic, it is important to acknowledge the extreme pressures on our health and social care systems and on frontline staff, during and following the pandemic period, as well as the painful impact on individuals and families.

There is widespread confusion and misunderstanding about DNACPR processes for patients and doctors, which can mean people are not prepared or supported around end-of-life decisions. This report and recommendations draw on significant evidence of the experiences and preferences of older people, disabled people and healthcare staff. It aims to shine a spotlight on this issue and show a path towards cultural and systemic change.

About DNACPR

DNACPR stands for do not attempt cardiopulmonary resuscitation.

DNACPR means if your heart or breathing stops, your healthcare team will not try to restart them. Cardiopulmonary resuscitation (CPR) is one intervention available to resuscitate patients and has a relatively low success rate, an average of 12% for out-of-hospital cardiac arrests to 24-40% for in-hospital arrests (British Medical Journal (BMJ), 'Patients overestimate the success of CPR').

DNACPR is sometimes called DNAR (do not attempt resuscitation) or DNR (do not resuscitate). We use DNACPR in this report.

Decisions about not resuscitating a patient, or about putting a DNACPR notice on a patient's record, are made by doctors and do not need patient consent. This can be an immediate clinical decision made when a patient is seriously unwell, or a decision that goes on a patient's records in advance and affects treatment at a later stage. But it is a legal requirement for doctors to consult with a patient about a DNACPR decision if they have capacity, and with their next of kin otherwise.

Patients will be resuscitated unless they have a DNACPR notice on their records.

A DNACPR notice refers to CPR only. It should not mean that someone will be denied any other care and treatment.

DNACPR decisions should be based on an individual's health and the likelihood that they will have a positive outcome from CPR. They should never be applied to groups of people (known as 'blanket' DNACPR decisions).

About advance care planning

The CQC (‘Protect, respect, connect: decisions about living and dying well during COVID-19’) says advance care planning gives people:

“an opportunity to think about what matters most to them and what level of care and treatment they wish to receive. These discussions can take place at any time. An advance statement may include details such as:

- where and how they would like to be cared for, for example, at home or in a hospital, a nursing home, or a hospice
- how they want any religious or spiritual beliefs to be reflected in their care
- practical issues, for example, who will look after their pets if they become ill
- what healthcare treatments they want, or do not want, as they near the end of their life
- who they want to be with near the end of their life.

As part of these conversations, there may be discussions about whether to attempt CPR if their heart stops or they stop breathing.”

The ReSPECT process or form is commonly used to guide advance care conversations in healthcare settings. We mention it throughout this report.

Language used in this report

Language is an important step in recognising people with respect and dignity. We have chosen to use the terms preferred by the people we have worked with in producing this report.

We use person-first language (for example, ‘people with Down’s syndrome’) when talking about the experiences of people with learning disabilities. This was the language chosen and used by the people we worked with, including people with learning disabilities, and is commonly used across the health service.

We use identity-first language (for example, ‘deaf people’) when talking about disabled people, including all disabilities. This was the language used by the people we worked with and organisations such as the Equality and Human Rights Commission. We recognise its connection to the social model of disability, which says disability is created by an inaccessible society.

We use the word ‘ageism’ to talk about discrimination based on age. We use the word ‘ableism’ to talk about discrimination based on disability.

Blanket DNACPR decisions and human rights

On 20 March 2020, the National Institute for Health and Care Excellence (NICE) released guidance stating: "all adults on admission to hospital, irrespective of COVID-19 status, should be assessed for frailty using the Clinical Frailty Scale (CFS) and that comorbidities and underlying health conditions should be considered."

On 25 March 2020, NICE issued COVID-19 rapid guidance for critical care in adults [NG159] to clarify that the CFS should not be used in isolation to direct clinical decision-making, and that doctors should make decisions about care together with patients and their carers where possible.

Different interpretations of this guidance led to allegations of blanket DNACPR decisions in hospital and residential care settings, especially for disabled people and older people (CQC, 'Protect, respect, connect'). Blanket DNACPR decisions are where DNACPR notices are put on groups of people's records because of their age, health condition or disability without considering them as individuals and without speaking to them directly. The lack of conversation and any discrimination involved in these decisions is illegal and breaches individuals' human rights. These rights and associated laws are outlined below.

Human rights law

R (Tracey) v Cambridge University Hospitals NHS Foundation Trust and others

David Tracey challenged a DNACPR notice on his wife Janet Tracey's medical file. She was diagnosed with terminal lung cancer and involved in a serious car accident the same month. Janet Tracey was considered to have legal capacity to make decisions about her care and treatment, but medical staff put a DNACPR notice on her file without her and her family's knowledge. The Court of Appeal made it clear that in decisions about treatment, including where a patient has a terminal illness, and in DNACPR decisions, Article 8 of the Human Rights Act 1998 applies. This protects the right to respect for private and family life. The court said there should be a presumption in favour of patient involvement in DNACPR decisions:

"The duty to consult involves a discussion, where practicable, about the patient's wishes and feelings that is better undertaken at the earliest stage of the clinical relationship so that decisions can be reviewed as circumstances change…the duty to consult is integral to the respect for the dignity of the patient".

Mental Capacity Act duties

Winspear v City Hospitals Sunderland NHS Foundation Trust

Elaine Winspear challenged the decision of medical staff to impose a DNACPR notice on her son Carl (who was 28 years old with cerebral palsy) without his family's knowledge. The court found this went against his Article 8 rights under the Human Rights Act 1998. The court was clear that section 4(7) of the Mental

Capacity Act 2005 (MCA) includes a duty to consult those identified in the section (such as family) unless it is not practical and appropriate to do so.

This means the decision-maker must take active steps to consult, rather than passively considering views that they may be aware of. Failing to meet this duty means the decision-maker cannot rely on the defence in section 5 of the MCA (which protects staff from legal responsibility if they have a reasonable belief that the person lacked capacity) in any claim that the person's human rights have been breached under the Human Rights Act.

How we did the research

We undertook five different types of research in a ten-month period to develop the evidence for this report. This involved listening to different groups of people to understand why DNACPR service failings keep happening.

- We looked at evidence from cases people have brought to us and analysed the common experiences, themes and issues.
- We carried out a survey of doctors of all specialisms and levels in the health service in England. Over 700 doctors filled in the online survey, which was open for four weeks in summer 2023.
- We commissioned independent research with older people and people with learning disabilities to understand their experiences and make recommendations about how the system could work better. Compassion in Dying and the BIHR held focus groups and interviews from August to November 2023. All participants were paid fairly and equally for their time.
- We held a focus group and interviews with nurses from across England who work with older people, people with learning disabilities and in palliative settings. We explored issues including their involvement in DNACPR decisions and how the process works for people with learning disabilities.
- We looked at reports and research produced in the past five years on DNACPRs and people's experience of the health system, focusing on disabled people and older people. The reports covered a range of perspectives, from practising doctors to member-led advocacy organisations. We also had conversations with report authors and relevant organisations to help guide and shape our research.

Doing the research in this way helped us make findings in different areas and make sure our approach was fair and balanced.

Main findings

1. Patients and families are not always told about DNACPR decisions

The most frequently upheld element of complaints to us about DNACPR notices involved conversations not happening or families not being informed. The case below shows this in practice. It also demonstrates breakdown of communication between settings and highlights the levels of distress this causes to everyone involved.

Case study 1: Patient and family not consulted

Ms H was in her eighties. In October 2016, she was taken to hospital, treated for a mini stroke and then sent to her local hospital. Her condition got worse in hospital and she sadly died shortly after. In April 2019, Ms H's sister, Ms R, became aware of the DNACPR decision that had been put on her sister's record. The record highlighted that Ms H was not consulted about the DNACPR decision as it suggested she did not have capacity at that time. In this situation, Ms R should have been informed about the decision and had not been.

We did not find enough evidence that Ms H lacked capacity to make the DNACPR decision. There was no reason why the Trust could not have discussed the decision with Ms H and Ms R. Due to a breakdown of communication between the two hospitals where Ms H received care, the Trust had started CPR on her despite a DNACPR decision being in place, which led to inappropriate resuscitation efforts happening. This was a failing. It caused Ms R to experience post-traumatic stress disorder (PTSD) and depression, and she needed ongoing therapy to process what happened.

Respondents to our survey with doctors suggested there is room for improvement in the way that DNACPR decisions are communicated. Just under half (46%) said there was good communication most of the time, with 43% saying some of the time. Just 5% said there was always good communication. But 95% said they were confident having discussions with patients, families, carers and advocates about DNACPR decisions.

Palliative medicine and geriatric medicine are two specialties where good communication about DNACPR decisions is particularly important. But the most common response within these specialties was that good communication takes place some of the time (62% for palliative medicine and 46% for geriatric medicine).

Research with older people and people with learning disabilities highlighted the importance, to patients from these groups and their families, of conversations about end-of-life care. Two-sided, respectful, empathetic communication enables care to be patient-focused and gives everyone involved the chance to offer their

perspective. When this does not happen, patients feel their role in their own care is disregarded, as can be seen in the case studies throughout this report.

> "I was told that continuing to treat me at this stage was bonkers and that I'd had quite a lot of money spent on me already."
> Compassion in Dying research, page 7

This is clearly extremely disrespectful and inappropriate. It also changes the quality of care that can otherwise be provided when both patient and doctor are on the same page.

Our evidence base suggests these concerns are worsened for people with learning disabilities and older people, due to fears around respect for individual autonomy in DNACPR conversations and decision-making processes. Contributors to research conducted by BIHR stressed that "decisions should be based on the individual's wishes rather than assumptions-made based on disabilities or health conditions" (BIHR, page 17).

> "I think it [the reason for a DNACPR] is unfair based on learning disability alone. Going through the work I do regularly and the campaigning group as well, this always gets brought up as being wrong on so many different levels, because doctors don't consult with parents. Parents are then on the back foot and have to fight. The process is so bad, it really is."
> BIHR, page 20

> "The only thing I own, I will ever own, is my life, and I want to decide about it. I don't want people to make outside decisions on if I have value, of course I have value, but that value is intrinsic to me. I must be allowed to make these decisions."
> Compassion in Dying research, page 8

Insensitive communication and barriers to good communication

As well as not communicating at all, we found substantial evidence around insensitive or uncaring communication.

Doctors told us that they had great empathy for patients and their families. But our evidence suggests that when time and clinical pressures meet to such an extent as in the COVID-19 pandemic, some patients are left to feel they are not a priority.

For end-of-life conversations, this can make patients feel that their life does not have value. We found that this can compound feelings of discrimination and unfair treatment. It can also cause distress for doctors.

Specific to the pandemic, doctors and nurses told us about the consequences of visitation restrictions on families' understanding of their relative's health and the effect this had on end-of-life conversations.

> "The challenge with the pandemic is that things were often done at a distance and remote. Communication would mainly be telephonic/zoom calls, etc. People were able to have sensitive DNACPR conversations over the phone but there is something about being in hospital, seeing a loved one deteriorate and understand the clinical reasoning behind why a clinical decision is made and being able to ask more."
> Survey response of doctor working in general (internal) medicine and geriatric medicine

> "Communication problems were highlighted as a big issue for everyone we spoke to. This includes instances where sensitive DNACPR discussions are held over the phone, which is seen as inadequate for such an important and sensitive subject, or no discussion is held at all."
> BIHR, page 26

Healthcare professionals have told us that for some people, especially those living in care or residential homes, their relatives may not have seen them physically for months. This meant that no matter how sensitive the doctor was in having an end-of-life conversation, families were more likely to be shocked, even in those cases when they had been kept informed of their relative's condition.

Positive experiences

Where people had had positive experiences of end-of-life conversations, Compassion in Dying's research suggested the important elements of a good conversation were:

- doctors 'owned' the DNACPR decision
- doctors explained why they had made that decision for that person, why CPR would do more harm than good, and what care and treatment the person would continue to receive
- doctors explained that, while consent was not needed for the decision, they wanted to establish a shared understanding of how the person would be cared for
- people were invited to ask questions
- doctors spoke with pragmatism and honesty
- doctors showed sensitivity and spoke with warmth and respect (Compassion in Dying, page 16).

2. Conversations often happen too late and in emergency settings

> "We need to be having these discussions earlier as a nation rather than leaving them for an urgent situation. This is where misunderstanding occurs due to high emotions on both sides."
> Survey response of doctor working in geriatric medicine

Most of the poor experiences, from focus group feedback, conversations with doctors and our complaints, related to acute hospital settings. Though this evidence shows these are not the ideal settings for conversations about end-of-life, we acknowledge this will sometimes be necessary. But all audiences who took part in our research felt there could be:

- a better balance with earlier planning in other settings
- support for better conversations to take place in emergency settings.

There is excellent experience within palliative, geriatric and learning disability healthcare staff, which could be shared with staff working in emergency settings.

> "People expressed that, at these times, emotions such as shock, fear and anxiety were already running high, the conversations were rushed, and they were not given time to reflect on the information. This contributed to a feeling of having something 'done' to you rather than it being an individualised, considered and sensitive discussion."
> Compassion in Dying, page 10

The cases below are examples of poor communication of DNACPR decisions in acute settings, including emergency departments and high dependency units.

Case study 2: Trust did not communicate with patient's family

Mr A was admitted to hospital in June 2018 for planned surgery to remove a tumour from his kidney. After surgery, Mr A went to the Trust's high dependency unit and then moved to the urology ward. Shortly after, he became unwell and was diagnosed with sepsis. His condition got worse and he sadly died. On the date of Mr A's death, doctors had spoken to his wife, Mrs A, and advised that her husband had rapidly deteriorated and was likely to die. But there was no reference to DNACPR. Shortly after this conversation, doctors made a DNACPR decision and completed the relevant documents.

While we found no failing in the clinical decision of the DNACPR, we found a failing in the Trust's communication with Mrs A about the DNACPR. This meant Mrs A was unprepared and in shock when she found out the Trust had not attempted to resuscitate her husband. This caused Mrs A considerable distress. She felt this made the grieving process worse.

Case study 3: Inaccurately recording family member's wishes

In April 2020, Mrs A's husband, Mr D, was admitted to hospital from the care home where he had been getting respite care. At the time, Mr D was in his seventies and had Lewy body dementia (a condition that affects thinking, memory and movement) and Parkinson's disease (a condition in which parts of the brain become damaged). Mr D was admitted to hospital with suspected COVID-19 symptoms. A doctor rang Mrs A to advise that CPR would not be in Mr A's best interests. Mrs A told the doctor she firmly believed the Trust should attempt resuscitation for her husband. Over the next few days, Mr D's condition got worse and he sadly died. Mrs A received Mr D's medical records and found they said she had agreed with the proposed decision not to attempt CPR.

While we found no failing in the clinical decision made about CPR, we found a failing in the Trust inaccurately recording Mrs A's wishes. This caused Mrs A further upset and frustration.

Time pressure and lack of experience leads to poor communication

It is clear the main problem with having and reviewing these conversations in acute settings is time, especially where rapid deterioration in health can happen.

> "Unfortunately, as much as people may be aware of the guidelines, we struggle to find time to have these discussions ahead of time, before people become unwell. We also don't continue the conversation as things change with time."
> Survey response of doctor working in emergency medicine

> "Colleagues are still reluctant or too time-pressured to have proactive conversations."
> Survey response of doctor with a non-clinical background

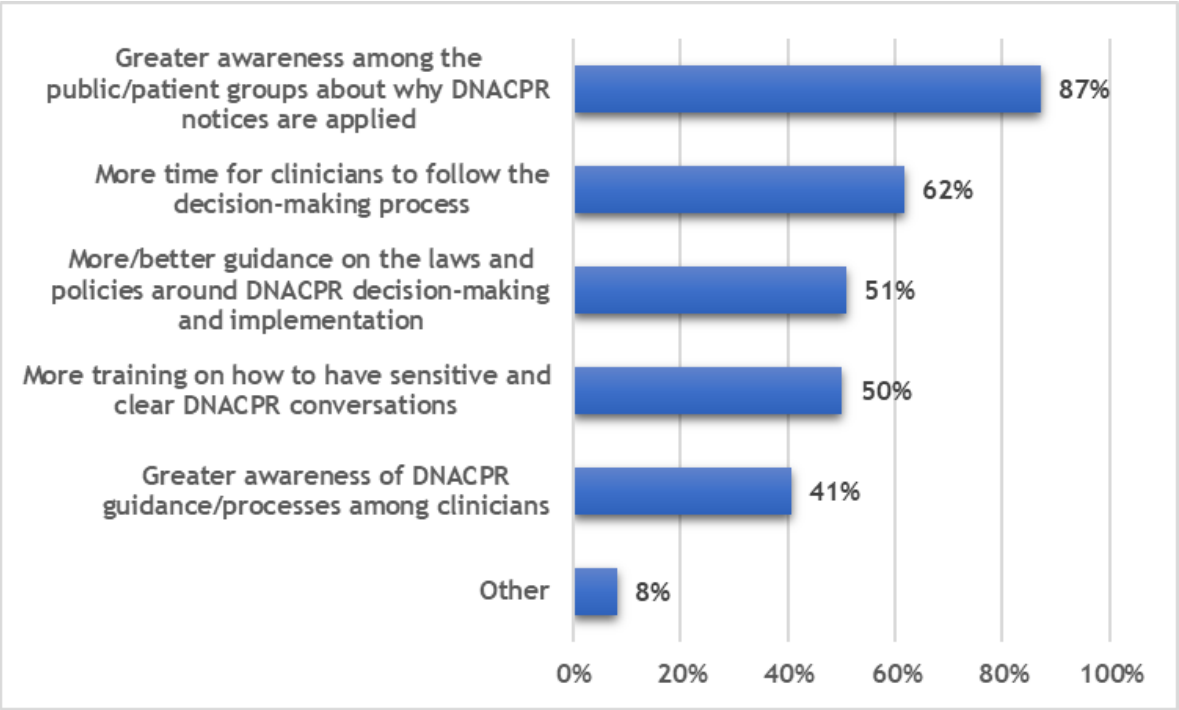
Where time was available, people told us they had more positive and empathetic conversations.

> "The difference is humanity. It's being willing to align yourself with a fellow human who's in more trouble than you are."
> Compassion in Dying research, page 16

> "The doctor wasn't talking as a doctor he was talking as a fellow human being. We'd been talking about music."
> Compassion in Dying research, page 16

As highlighted in the graph below, doctors point to time and training as issues that need to be addressed in the DNACPR process to enable better quality, rights-respecting conversations to take place. Half of doctors who responded to our survey, across different specialisms, asked for more training on how to have sensitive and clear conversations. This suggests experienced doctors accept this is an area for development and welcome support.

Figure 1: What might help address the issues and barriers to managing the DNACPR decision-making process effectively?



Source: PHSO's survey of doctors, 2023

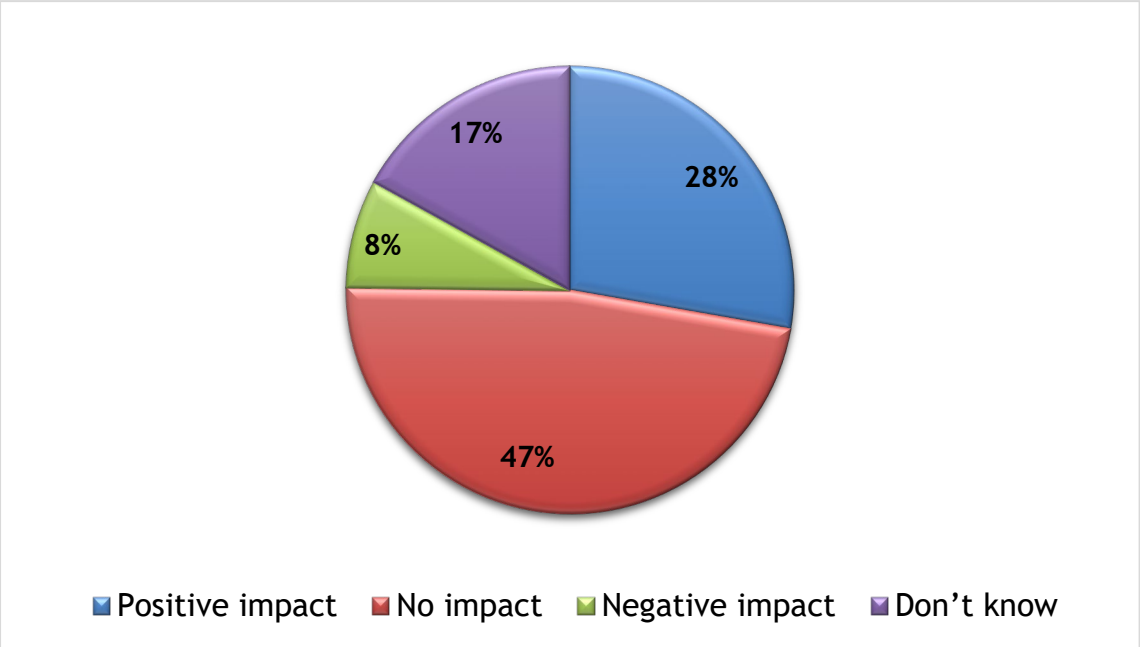
Advance care planning

Our research points to advance care planning as a partial solution to improving communication around DNACPR decisions. Our evidence suggests that opportunities to have these conversations early are often missed and that the tools available such as the ReSPECT forms and advance care principles are not always used. Trusts are not encouraging thinking about end-of-life conversations in enough settings.

As part of the DNACPR survey we asked doctors if they were aware of the advance care principles, which had been produced in response to the CQC report and overseen by the MOG on DNACPRs.

53% of doctors had heard of the Universal Principles for Advance Care Planning and 47% had not heard of them at all. Awareness levels were highest among respondents specialising in end-of-life care and those working in palliative medicine. Those who were newer in their roles (less than two years) had the lowest awareness levels (22%), suggesting that more work is needed to embed these principles.

Figure 2: What impact, if any, do you think the Principles have had on how DNACPR notices have been applied since March 2021?



Source: PHSO's survey of doctors, 2023

> "There are issues around awareness, understanding and education that need addressing, and more and better guidelines help to some degree, but primarily there are systems issues that mean that these guidelines cannot be actioned in practice; therefore it is a systems approach rather than educational/guidelines approach that requires implementation."
> Survey response of doctor working in general practice

Where conversations happen ahead of time, the ReSPECT form does seem to enable these discussions more holistically than a DNACPR form.

> "ReSPECT does allow a more nuanced approach to what is right for the patient."
> Survey response of doctor working in cardiology

But there needs to be adequate time and training to complete these.

> "ReSPECT gives the opportunity to provide much more detailed recommendations about the patient's wishes and priorities, and what specific medical treatments they would and wouldn't want. Unfortunately, this is not always completed as well as it could be … this is down to the clinician not the form."
> Survey response of doctor working in geriatric medicine

Nurses already play an important role as interpreters and challengers around DNACPR decisions. They are vital to conversations taking place in more appropriate formats and settings. Nursing staff are a crucial part of accountability in all care settings, where needed, clarifying and challenging conversations and decisions as people who usually know patients and their individual needs on a different level from doctors.

While all the nurses we spoke with felt they would be able to challenge a poor DNACPR decision, they acknowledged that this is unlikely to be the case for more junior healthcare staff, some of whom are likely to have closer relationships to the patient involved in the decision.

Nursing staff in one trust developed their own solution to this. Junior nurses felt opportunities for advance care planning conversations were being missed for their patients. Senior nurses produced a document containing criteria which, if matched with the patient, empowered junior nurses to recommend an advance care planning conversation to the doctor. This encouraged a 'speak up' culture. It also promoted good multidisciplinary team working, which was considered as important in making sure well-rounded decisions can be made about advance care planning.

Including people with different communication needs in advance care conversations

People with learning disabilities may need more time to process what end-of-life conversations will mean for them. Advance care conversations are vital to making sure people with learning disabilities are included in decisions about their healthcare and their rights are upheld.

> "People with learning disabilities need sufficient time to process information and make informed decisions about DNACPR. Rushing the decision-making process is viewed as problematic and may prevent individuals from being able to make an informed decision about crucially important healthcare."
> BIHR, page 19

> "People with learning disabilities should still have the same rights as people without a learning disability, it might just be that it takes a little bit longer for them to be able to understand what you're actually talking about."
> BIHR, page 6

Learning disability nurses also said that conversations often happen too late or at an inappropriate time for people with learning disabilities. Moving to an advance care planning approach would make sure conversations can happen at the right time, in the right context (such as community settings) and with someone the patient knows. This perspective was also reflected by nurses working with older people and in palliative settings.

In 2017, annual health checks became a way to offer a separate end-of-life conversation for people with learning disabilities. While we encourage annual health checks as a way of having end-of-life conversations in a more appropriate setting, our evidence suggests that this is not always happening. If effective, this could cover 320,000 people (NHS England, 'A summary and overview of the Learning Disability Annual Health Check electronic clinical template').

For older people, nurses suggested considering the benefits of having advance care conversations in residential settings for those living with frailty. Where possible, this would avoid these conversations happening for the first time in acute settings.

More pathways for conversations

Overall, evidence suggests that there is no quick fix. There need to be whole-system changes to make sure these important conversations happen in settings where patients feel comfortable and doctors have time.

There is no one clear pathway for these conversations to take place. Our research showed there needs to be more options for end-of-life conversations to happen at the right place and time for individuals, with more healthcare staff equipped to have them. Confining conversations about end-of-life to one healthcare setting (such as care homes) would not account for people's individual needs and could reinforce discrimination.

If more pathways open up for patients to have discussions about their end-of-life wishes, cultural issues would still need to be addressed to encourage proactive conversations. These issues prevent conversations about death and dying from happening more naturally between the health service and patients earlier in people's lives. This leaves people and their families unprepared when the time comes for conversations about end-of-life care (K. Mannix, 'With the End in Mind').

3. DNACPR conversations are often left to family members as patient's wishes have not been discussed before it is too late

> "I accepted, on behalf of my husband, that he wasn't going to survive. I just hope I made the right decision, because that was a big responsibility."
> Compassion in Dying research, page 9

Families generally did not want responsibility for deciding whether their relative should have a DNACPR notice and preferred this to be a clinical decision. One person said they felt like 'a murderer', making decisions that have haunted them. This finding also emerged from our conversations with nurses and a research study carried out with families who discussed a DNACPR on behalf of a relative during the COVID-19 pandemic (Tomkow et al, 2023).

People emphasised that they do want their families to be involved. But they want this to happen earlier in the process as a support to their decision-making, rather than their family members making the final decision.

> "If I was in a condition where I couldn't make my own decisions, I would want my partner to be allowed to help make the decision as well as my father."
> BIHR, page 1

The BIHR report (page 8) says doctors should: "Always involve individuals' families and loved ones in DNACPR decisions to aid understanding and provide emotional support to the individual. But also respect when a person with learning disabilities does not want other people involved; it should be their choice."

This relates to the spike in complaints we received from families during the COVID-19 pandemic when they were not able to advocate for their loved ones or felt unable to navigate the health system with them.

Case study 4: Clinical DNACPR decision not communicated to family member

Mrs F's husband, Mr F, fell at home in June 2020 and needed hospital treatment. Because Mr F had dementia, Mrs F had a power of attorney for health and welfare, which meant she should be involved in discussions around his treatment and care.

The doctors treating Mr F made a DNACPR decision for him. Records show doctors intended to discuss this with Mrs F, but she was never told about the decision. Sadly, Mr F died while he was in hospital.

We found no failing in the clinical reasoning of the DNACPR decision, but we found a failing when doctors did not communicate their decision with Mrs F.

Due to visitation restrictions in place at the time, Mrs F was unable to be with her husband for some of his time in hospital. This made it even more important that she understood what decisions doctors were making and why.

This event had lasting and profound effects on Mrs F, which could have been lessened had the Trust fully explained the DNACPR and the reasons for it.

Case study 5: Family member made aware of DNACPR in coroner's information

Mr F's wife, Mrs F, was taken to hospital in May 2021 as she had fractured her hip and needed surgery. Unfortunately, Mrs F died from a heart attack shortly after surgery.

Mr F held a power of attorney for health and welfare for Mrs F. He was unaware that doctors had made a DNACPR decision following his wife's admission to hospital. He only became aware when the coroner sent information to him around six weeks later. Mrs F's records said that Mr F had agreed to the surgery and the DNACPR decision.

While we did not find a failing in the clinical decision to apply a DNACPR, we did find the Trust failed to communicate with Mr F about this. Finding out this information was devastating for Mr F and had a lasting impact on him.

4. There is a lack of accessible information given at the time or before DNACPR conversations

Given the complexity and misunderstanding surrounding DNACPR conversations, providing clear information should be a priority.

People with learning disabilities told us that the NHS should be:

- offering DNACPR information in easy read formats
- providing audio versions for people with reading difficulties
- proactively offering accessible materials without needing requests
- providing consistent, accessible information in doctor's surgeries (BIHR, page 21).

This was also reflected by doctors who do not feel they have clear information, support or experience, especially when working with people with additional needs.

> "Support for doctors when managing specific groups - I'm thinking about learning disability patients and those with premature frailty/high care needs at a young age where I think this is often handled less well. There is also something about transitions of care from childrens' to adults' services in those with short life expectancies but where patients are living to adulthood where historically they wouldn't - adult doctors then struggle to manage decision-making and I have had personal experience of a couple of truly heartrending and distressing cases for all involved."
> Survey response of doctor working in acute internal medicine

Learning disability nurses and people with learning disabilities also advocated for more accessible material to improve conversations.

> “Don’t assume all people with learning disabilities like Easy Read because some like Plain English as well.”
> BIHR, page 21

> “In my doctor’s surgery there’s only two pieces of information that is Easy Read. Everything else, nothing.”
> BIHR, page 1

> “Just because he is non-verbal does not mean to say that he cannot communicate.”
> BIHR, page 1

Nurses and doctors also said cultural, linguistic and religious differences can add complexity to conversations around death and DNACPRs.

> “[We need] published guidance on patient's religious views around DNACPR and ethical concerns around this.”
> Survey response of doctor working in general practice

In its 2022 report, the Learning Disabilities Mortality Review Programme (LeDeR) said reviewers judged that appropriate accessible communications were provided in 60% of DNACPR discussions.

> “This is hard to understand and needs to be explained in a way all those involved can understand. Simplifying the language and acronyms employed in DNACPR discussions will increase accessibility and comprehension for a wider audience - this is very important to people with learning disabilities.”
> BIHR, page 23

It is important that healthcare staff proactively offer accessible communications, rather than people having to request them. This upholds people’s rights and access to equitable healthcare.

Equity of access to care is the responsibility of ICBs, which can commission the design of resources where they are lacking or pay for existing resources designed by external organisations.

A recent review of ReSPECT for people with learning disabilities by Warwick University came to this same conclusion and researchers worked with a Leeds-based service to co-design easy read resources for use in tandem with the ReSPECT process. Similarly, the Victoria and Stuart Project and No Barriers Here projects have co-designed resources to help people with learning disabilities plan for the end of their life. This toolkit will be available in summer 2024. This best practice is encouraging and shows the benefits of co-designing resources.

5. There are issues with record-keeping and documenting decisions

While a DNACPR decision should be logged on patient records, this is not accessible across the health and social care system and there are often problems with advance decisions being logged, updated and respected.

We found repeated evidence of DNACPR decisions not being recorded or shared properly between settings. This particularly affected people who had made advance care decisions with their GP or another healthcare professional. The lack of a joined-up digital system is causing painful, repeated conversations and frustration. Our research showed that in some instances people were going to extreme lengths to have their wishes listened to, such as wearing DNACPR jewellery and always carrying their form with them.

> "My husband had a DNR. When he became unconscious, the doctor told me that they were going to do something to bring him back. And I said, but he signed a DNR, don't do this, and they made me feel like a murderer. But I wouldn't allow them to do it, he was dying of cancer anyway; we knew he was dying and he died calmly within forty-eight hours. But they really did make me feel like a murderer, like a wicked woman. It took me a long time to recover from how awful they made me feel."
> Compassion in Dying research, page 12

This was also reflected for people with learning disabilities. There is a need to "build on the electronic system's capacity to flag DNACPR preferences, diminishing the reliance on physical documents such as the yellow envelope, which can be difficult to locate, particularly during times of heightened stress" (BIHR, page 24).

There are inconsistencies between trusts in how patients with learning disabilities are identified and how DNACPR decisions are monitored. NHS England developed the learning disability improvement standards in 2018 to help trusts measure the quality of care they give to people with learning disabilities, autism or both. Alongside this, the NHS Benchmarking Network was commissioned to collect annual data to understand compliance with the standards. While it is not mandatory, over 90% of NHS trusts have taken part. HSSIB recently recommended continuing the benchmarking survey to make sure local population needs are met (HSSIB, 'Investigation report: caring for adults with a learning disability in acute hospitals').

In the most recent benchmarking report, 54% of trusts surveyed did not monitor rates of DNACPR decisions for people with learning disabilities. This was highlighted as an area to improve.

Enabling better record-keeping was a common theme among all groups we heard from, including doctors:

> "There needs to be a form that is accessible by all healthcare providers (would need to be electronic) and patient or NoK [next of kin], this would prevent discussions being unnecessarily repeated and encourage explicit descriptions of discussions held and clinical reasoning behind such discussion. This central form could then be reproduced in physical notes if needed."
> Survey response of doctor with dual specialty

> "When DNACPR conversations have taken place with a person these decisions do not follow the person from care setting to care setting, subjecting the person to repeated conversations, bureaucracy and disjointed care."
> Survey response of doctor working in palliative medicine

> "The form either needs to be carried with patient or be electronic with access to all health care."
> Survey response of doctor working in general practice

For people with learning disabilities, there is also no national shared system for storing and managing information about their needs, including the reasonable adjustments needed for each individual, as noted in HSSIB's report.

Even where a person's medical record is updated with a DNACPR decision, this will not be accessible in care homes or ambulance services, which are common points of implementation. Findings from our casework and research reports, which show DNACPR notices not being seen and adhered to, highlight that any system needs to be accessible across these services as well as in hospitals and GP practices.

There is concern that any work to move conversations from urgent care to advance care planning will be ineffective if conversations are not recorded in a functional, accessible system that doctors can regularly update and check. The MOG and 2021 CQC report recognised this and recommended a single digital system (Department of Health and Social Care, '17 May Summary note of meeting', but this is yet to happen and progress is unknown.

In the following case, a patient's record was not updated properly, so previous information was not taken into account.

Case study 6: DNACPR decision not updated

In January 2021, Mr A was admitted to hospital with abdominal swelling and distension (bloating). Mr A had multiple health conditions. Doctors diagnosed him with a bowel perforation (hole) and found a saddle pulmonary embolism. This is when a large blood clot sits on top of the main pulmonary artery between the lungs. Doctors decided to treat this with blood-thinning medication and Mr A was discharged. He was readmitted six days later and sadly collapsed and died in hospital shortly after.

After Mr A had collapsed, a DNACPR form had been completed and recorded that doctors had spoken with Mr A's partner about the decision. But we found this was based on a previous discussion and had not been properly reflected in the documentation. While we found the DNACPR put in place was clinically made within the relevant guidelines, the Trust failed to correctly document the communication it had had with Mr A's partner about this decision, causing her to lose faith in the Trust.

There is not enough space on forms to record conversations accurately

We found there is not enough space on every DNACPR form to accurately and precisely record DNACPR conversations and their outcomes.

70% of doctors who completed our survey thought the current DNACPR form was fit for purpose. But doctors working across different specialisms told us there was not enough space to accurately summarise the complexities of DNACPRs conversations. There is no standard DNACPR form, so this will not be the case for all trusts. Some trusts ask doctors to fill in a separate sheet to document the conversation and attach it to the patient's notes.

> "No form can deal with the complexity of the issues which can be involved so can only be an adjunct to care. Current forms are a tick box exercise. Simplify them and allow back-up discussion to be recorded in the notes. The form should be seen as similar to operative consent and use that model."
> Survey response of doctor working in acute internal medicine

> "There is not enough space on the form to write much detail about the conversations that happen, the clinical conditions that lead to the DNACPR decision or much free text space."
> Survey response of doctor working in general practice

This lack of space particularly affects patients who have complex health conditions. It pushes doctors to decrease the complexity of the information so that it can fit on the form. There should be a standard approach to allow for transparency and consistency.

6. People voiced genuine fears about ageist and ableist attitudes and behaviours in the NHS

Across our engagement with different groups, academics and organisations, there was a concern that ageist and ableist attitudes are present in the NHS and affect care. This was also an important finding in HSSIB's recent report.

> "They were hell-bent on bumping me off and getting me to agree to this thing."
> Compassion in Dying research, page 7

Services are not consistently joined-up or responsive to the needs of older people living with frailty, as recognised by the NHS Long Term Plan. Nurses we spoke with noted that older people can often be asked about DNACPRs multiple times in hospital settings. While it is important to regularly review throughout people's lives, moving towards better advance care planning would allow the time and space needed to have this important discussion. Older people often just want an opportunity to discuss their plans and care with personalised support.

Discussions do not take place due to perceived distress for patients

During the learning disability nurses focus group, there was reference to the General Medical Council's guidance on CPR decisions. The guidance suggests doctors do not have to have a conversation with a patient if they think it would cause them 'serious harm'. There was experience of this being interpreted as 'distress' and providing reason for a conversation not to take place. It was agreed there is likely to be actual or perceived distress for many patients with learning disabilities, but this is not a reason not to have the conversation.

Participants in our research also suggested concern that the bias and prejudice of healthcare professionals could affect decision-making. Some indicated that media coverage and their experiences during the COVID-19 pandemic had made this worse.

> "Several people believed that, if over the age of 80, a DNACPR decision is automatically made, some people believed this system was introduced during the Covid-19 pandemic. People also talked about how badly society treated older people in the UK. Some felt the NHS and Government lacked humanity, empathy and compassion and that blanket DNACPR decisions were a symptom of this."
> Compassion in Dying research, page 7

Learning disability nurses gave the example of assumptions that people with learning disabilities cannot 'handle' a conversation about DNACPR or death. This was not their experience, particularly if conversations are delivered in an accessible way that patients with learning disabilities, and their family and carers, can understand and engage in.

> "Having the do not resuscitate, it's got to be everybody's personal decision. Just because you've got a learning disability or physical disability does not mean to say that you cannot make a decision with support."
> BIHR, page 1

Doctors, nursing staff and patients said further training around managing these conversations when working with disabled patients would be useful to build empathy and understanding of rights in clinical practice.

Diagnostic overshadowing

It was concerning that diagnostic overshadowing was raised during conversations with stakeholders across the system, from healthcare staff to member-led organisations. According to NHS England, diagnostic overshadowing happens "when the symptoms arising from physical or mental ill health are misattributed to a person's learning disability or autism leading to delayed diagnosis or treatment" (NHS England, 'Clinical guide for front line staff to support the management of patients with a learning disability and autistic people – relevant to all clinical specialties').

The groups we heard from were deeply worried about diagnostic overshadowing. Any training on DNACPRs needs to make it clear that this is a service failing, breaches patients' rights and should be challenged if witnessed in practice.

Learning disability nurses gave examples of terms such as 'learning disability' and 'Down's syndrome' being used on DNACPR forms, despite there being other medical reasons for the decision. In these instances, the language was challenged by the nurses and changed. But it was recognised that not all healthcare staff would feel able to challenge this, particularly those at a junior level.

Diagnostic overshadowing and the COVID-19 pandemic

We heard repeated testimony from people with learning disabilities, and healthcare professionals who work with them, that they felt the COVID-19 pandemic was a setback in terms of attitudes around learning disability and how people with learning disabilities are prioritised in healthcare.

> "It just makes me feel like if you have a disability your life is worth less than a person that hasn't."
> BIHR, page 1

> "People with learning disabilities, their families, carers, and supporters, repeatedly share concerns about differential treatment, which is worse, on the basis of learning disability, throughout DNACPR decision-making, systems, and processes."
> BIHR, page 36

Accountability for this lies with the broader system as well as individual healthcare professionals who have collective responsibility to consider people's rights, no matter the situation. A perception that some people's rights around end-of-life care were not prioritised during the COVID-19 pandemic has had a lasting impact on trust for older people and disabled people.

Failings in applying and communicating about DNACPRs based on ableist and ageist attitudes

The case below shows what can happen when human rights are not taken into account in the DNACPR process. It is an example of when someone did not want a DNACPR notice on their record, but this issue goes beyond DNACPRs. It is about the perceived value of people's lives and people's wishes for the end of their life not being understood or, in some cases, respected.

Case study 7: Learning disability and mental health condition documented as reasons to not resuscitate

Miss F's sister, Miss M, was in full-time residential care. She was in her fifties and had diabetes, high blood pressure, learning disabilities and schizophrenia. She was admitted to hospital in April 2020 with suspected COVID-19 symptoms but was discharged back to her care home to be treated in isolation. Miss M's condition got worse, and she was admitted to hospital twice more over the next few weeks. During her first admission, a DNACPR decision was made for Miss M, referring to 'frailty' and 'poor physiological reserve' as reasons for not recommending CPR. It also said there was no discussion with Miss M as she did not have capacity, but that a discussion had taken place with her mother and Miss F.

Two days later, during her second admission, a second DNACPR decision was made referring to Miss M's frailty, poor physiological reserve and multiple co-morbidities (having more than one health condition at the same time). The form also said this had been discussed with Miss M's mother and Miss F.

During her third admission, another DNACPR form was completed and referred to Miss M being frail, having a learning disability, being dependent for daily activities and having schizophrenia. The Trust ticked the box reflecting that the decision was not discussed with Miss M's next of kin or carers, but it did not give a reason for this. During this admission, Miss M sadly died following a heart attack.

We found failings in relation to the DNACPR decisions the Trust made for Miss M, which added to the significant distress Miss M's family experienced. We found that:

- doctors should not have used the clinical frailty scale (CFS) to assess Miss M. The NICE COVID-19 rapid guideline at the time explained the CFS should be used when appropriate to assess baseline health and inform treatment decisions. It advised that the CFS should not be used to assess people with learning disabilities or with stable long-term disabilities
- there were conflicting notes about Miss M's mobility and the level of help she needed with daily activities. The Trust's entries appeared to be incorrect and painted a worse picture for Miss M when compared with information from her care home and family. This likely gave the medical team the impression that she had poor functional reserve and poor capacity to recover from severe illness
- Miss M's DNACPR forms and medical records did not provide evidence that the Trust's decisions were carefully considered in the context of her background health conditions and usual functional abilities. This does not reflect the FREDA principles of fairness, respect, equality, dignity or autonomy
- there was no evidence that the DNACPR decisions were fully explained and discussed with Miss M's mother or Miss F. The Trust missed opportunities to involve Miss M's family in its decision and show that Miss M was being treated as an individual.

Case study 8: Older person was not communicated with about a ReSPECT form filled out for her in hospital

Mrs R was in her eighties. She went to hospital for a scheduled knee procedure for an existing chronic condition. Mrs R had a fall in hospital and needed further rehabilitation in October 2019. In March 2020, the doctor treating her completed a ReSPECT form which said Mrs R did not wish to be resuscitated in the event of a cardiac arrest (when the heart stops pumping blood around the body). A few days later, Mrs R became aware of the DNACPR and discussed this with a ward matron, stating she was not happy with the decision. She was then discharged to a care home and the Trust sent the ReSPECT form to the care home approximately a week later.

We found that it was likely the Trust did not communicate effectively with Mrs R about the DNACPR decision. It also failed to make detailed notes of the conversation about the ReSPECT form in Mrs R's records. These failings caused Mrs R to experience significant stress and upset, which had a lasting impact on her.

7. There is a lack of public awareness and knowledge about DNACPR

Throughout our research, public awareness of the realities of CPR and knowledge about DNACPR notices was mentioned by doctors, nurses and members of the public as an area for improvement. This is also implied in complaints we have received where patients and their families have challenged a DNACPR notice, but we have often not upheld this part of the complaint due the clinical nature of the decision.

> "When some people found out about a DNACPR decision and were not asked for their consent, they were angry that the decision was imposed on them because they felt they had a right to be asked for permission. This common misconception urgently needs to be addressed."
> Compassion in Dying research, page 8

Public perceptions of DNACPR processes are often different from the reality. Our doctor's survey highlighted some frequently misunderstood points about DNACPR, including that:

- applying a DNACPR notice is an evidence-based decision about the likelihood of the patient's recovery and does not mean other treatment should not be given
- survival rates from CPR are poorer than they are often assumed to be, between an average of 12% for out-of-hospital cardiac arrests to 24-40% for in-hospital arrests (BMJ, 'Patients overestimate the success of CPR')
- even when CPR is successful and the return of spontaneous circulation (ROSC) is achieved, patients will often be too ill to have an acceptable quality of life
- patients and next of kin believe they have the right to request CPR as an option, rather than it being a medical decision made by the doctor.

87% of doctor respondents said more public education was needed around CPR and DNACPRs. To achieve this, many respondents, along with other healthcare professionals we spoke with and the Compassion in Dying research, recommended a public information campaign and information for an audience as young as school pupils around death and dying, the realities of CPR and DNACPR. The MOG recommended this to the Department for Health and Social Care, but it has not been actioned.

Improving understanding could help patients and their families and carers engage in conversations about DNACPR and death more generally. It would also allow patients to prepare in advance so that when the conversation happens, it does not come as a shock.

This was reflected in evidence from focus groups with people with learning disabilities, where there was confusion on rights around DNACPRs and a perception that the notice could also deny further treatment. It was also the experience of some clinical stakeholders we spoke to. The perception that DNACPRs symbolise a 'ceiling of care' is damaging trust around DNACPR conversations as a whole.

Too often in our research we heard from family members distraught about making what they saw as decisions on whether their loved one should live or die, which were never their decisions to make. We hope this report can help to start a more open conversation about death and dying among the general public and in the health service.

Recommendations

If you build a system to support the most underrepresented and underserved, it should serve everyone better. That is the basis for these recommendations. Changes made with the most affected groups at the heart of thinking should make end-of-life care work better for all.

These recommendations are a single package to improve the process surrounding DNACPRs. We have grouped them into four themes: training, regulation, communication and record-keeping.

1. Training

We recommend that:

1.1 All CPR training for all doctors and nurses should include scenario-based training on DNACPR (aimed at all NHS-funded providers). This part of the training should be co-designed with older people and disabled people.

This recommendation is aimed at:

- existing clinician training
- Royal Colleges
- universities (via Council of Deans of Health)
- NHS Employers
- Resus Council annual CPR training and universities as external CPR providers for some NHS trusts.

The training should have clear learning outcomes, covering:

- the legal requirement to communicate a DNACPR decision to the person (or someone close to them if they lack capacity to engage in a conversation about DNACPR) unless it is likely to cause the person harm
- communicating the decision using a human rights-led approach
- what is meant by appropriate documentation of DNACPR conversations and decisions, including what is expected on the form and why accountability matters
- examples of good practice conversations, including the importance of empathy in conversations and de-escalation

- what to include in a DNACPR conversation (an example of this is outlined on page 20 in Compassion in Dying's recommendations)
- what cannot be included in a DNACPR conversation
- clear signposting to existing guidance on DNACPRs and working with patients with specific needs
- using accessible materials to support discussion
- when to include advocacy services and other trained staff to support conversations, and where to find them.

The CQC has previously recommended national implementation of the ReSPECT form in advance care conversations (CQC, 'Protect, respect, connect'). If this were to happen, we recommend that training on ReSPECT should be brought into any training on DNACPR conversations.

We recommend that training needs are built into pre-existing training to make sure all necessary healthcare staff are covered.

Training all doctors and nurses also covers redeployment of staff in national crises. It could also help to reduce complaints about health settings where staff have been moved away from their areas of specialism in any future national crises.

There is a gap in existing training around learning disability and autism, in terms of learning outcomes. We were unable to find evidence of any learning outcomes attached to NHS England's Core Competency Frameworks for doctors on learning disability and autism. This means no training related to learning disability and autism has learning outcomes at present. This needs to be addressed urgently.

Government and our health service need to recognise that when national crises happen, disabled people and older people may be more affected than others by restrictions in communication, access to existing support and contact with doctors. For future national crises, proactive action needs to be taken to support the requirements of the most underserved groups as in Article 11 of the Convention on the Rights of Persons with Disabilities (CRPD).

If this training is co-designed and delivered by people with learning disabilities and older people, it would be a positive step towards including people using the NHS in service improvements. Royal Colleges, universities, ICBs and Foundation Trusts should work with local, experienced, member-led organisations to commission them and people they work with to co-design this training alongside doctors.

2. Communication

We recommend that:

2.1 ICBs should make sure that accessible communication materials, which meet the needs of their population, can be accessed through health settings to support patients, families and carers when having DNACPR conversations.

2.2 The Royal College of GPs, the Royal College of Physicians and the Royal College of Nursing should develop guidance for GPs, physicians and nurses working in acute care, to promote earlier conversations with patients, families and carers about wishes at the end of life and about advance care planning.

2.3 NHS England and ICBs should expand the number and type of staff who can formally support DNACPR conversations in multiple settings. This should include nursing staff, acute liaison nurses, local advocacy services and learning disability nurses. NHS England and ICBs should also recognise the importance of families and carers in supporting these conversations.

Accessible communication materials are not available as standard to support advance care or DNACPR conversations. This is a particular concern in acute settings where people may be less able to access support staff or staff trained to support advance care planning.

These resources should be commissioned or designed by ICBs (with local experts and organisations) as the institution responsible for equitable access to healthcare in their local area. During the design process, different materials should be considered for advance conversations and for conversations in emergency settings.

Any communication materials produced need to outline people's rights clearly and legally, including:

- consultation
- laws relating to mental capacity
- the clinical, but non-legally binding, nature of the DNACPR decision and how to challenge this.

There is existing best practice in this space, including a recent research study on the use of ReSPECT forms to support end-of-life conversations with people with learning disabilities, as well as information from Compassion in Dying and other

member-led organisations. Where these resources already exist and are relevant, they could be commissioned directly.

Settings for conversations

We recognise that a lack of time in the NHS is not easy to resolve, so we are not recommending one specific pathway for these conversations to take place. There is additional risk in recommending a setting based on age or other factors, such as entry into care homes or health MOTs, which could unintentionally reinforce damaging stereotypes, as explored in the report.

Instead, we recommend that the settings for these conversations are expanded formally, included in guidance and regulated.

Below are several recommended pathways. These are not exclusive, and any final decisions on formal pathways should be determined by NHS England in consultation with ICBs, Royal Colleges and member-led organisations.

- **GP practices.** Conversations should be proactively suggested by GPs. GPs should be open to end-of-life conversations requested by their patients and record them accordingly.
- **Annual health checks.** Annual health checks take place each year for people with learning disabilities. They are designed to give people dedicated time with their doctor to discuss their health, and for doctors to provide individual support and have a chance to spot underlying issues quicker. At present, there should be 320,000 people a year having annual health checks in England. The NHS England template for annual health checks includes end-of-life conversations, but there is currently no way to investigate how many of these are taking place. This pathway allows people to have the appropriate support of a family member or advocate present, and for people to be proactively given accessible communications and time to think about their wishes.
- **Acute liaison nurses.** We recognise acute liaison nurses' roles in care as a golden thread holding several of these recommendations together. But they are not available in every hospital setting and, as yet, there is no standard practice. Increased resourcing for these staff would support better outcomes for people with learning disabilities in acute settings.

Staff to support conversations

As in our recommendation on training, we are recommending that the number of staff who formally support end-of-life conversations should increase.

Learning from the COVID-19 pandemic, any advocacy support that is offered should follow patients through the end-of-life process. This did not happen in the last national crisis, which allowed patients to reach the end of their life without doctors understanding their needs.

Doctors should still be responsible for the clinical decision over DNACPRs, but this should always be made in conversation with the patient (and, where necessary, family members and carers) in line with current laws and guidance.

3. Regulation

We recommend that:

3.1 The CQC should update cross-sector guidance underpinning regulations to include planning for health inequalities in end-of-life care.

3.2 The CQC should make sure that assessment of providers' compliance with standards of good practice around DNACPR is strengthened in its regulation of all services, with a particular focus on improvement in secondary care services.

As the CQC is currently looking at its guidance covering regulations, there is an opportunity to make sure the guidance considers the evidence we have seen of health inequalities in end-of-life care. Examples include providing accessible information before end-of-life conversations and regulating annual health checks for people with learning disabilities.

At present, inspections of GP practices ask whether annual health checks are completed. But they do not assess the value of these checks for patients or look at whether the template for annual health checks has been followed. The annual health check template includes end-of-life conversations, but it is not possible to determine how many of these conversations are taking place or their quality.

4. Record-keeping

We recommend that:

4.1 NHS England should make sure, for advance care planning conversations, the primary care electronic patient record (EPR) is the single place for holding end-of-life care plans and DNACPR records. This should feed into the multidisciplinary shared care record and be accessible across all health settings. This needs to enable immediate digital access across all NHS provider organisations for healthcare staff and patients. Improving the interoperability of patient records would have far-ranging benefits beyond end-of-life care planning and achieving a single shared care record should be the ambition as soon as is practically possible.

4.2 NHS England, ICBs and trusts should make sure DNACPR decision-making tools include clear guidance on legal duties for doctors.

4.3 NHS England and healthcare providers should make sure there is more space to document conversations and decisions on DNACPR decision-making forms.

A joined-up approach

A lack of record-sharing between care settings has been raised consistently through our research and the work of others.

A single access point for DNACPR records to be available digitally by all healthcare providers would reduce duplication of DNACPR conversations. An example of this approach has been introduced by Universal Care Plan for London.

A potential pre-existing option for allowing patients to access their records would be to use the NHS app to store DNACPR decisions, as is being taken forward by the 'Mobile First' approach. This could follow the documentation of other decisions in the app, such as organ donation. If followed, owing to accessibility requirements, the NHS app should not be the only place this decision is held. Like organ donation, it should be one of the spaces accessible to both the patient and the healthcare system.

We are aware that care plans are available digitally in almost half of ICSs nationally, but the geographical inequity of this approach and variation of maturity of these systems still needs to be addressed. Due to a lack of standardisation in digital systems, there is inconsistency in how DNACPRs are flagged on a patient's record. Where care plans are available digitally there is also variation in take-up by doctors because this approach has not been embedded in their workflow. Where digital care planning is available, we recommend that ICSs include this in DNACPR and end-of-life conversation training.

NHS health and social care passports are another mechanism that currently exists to improve and simplify the healthcare experience of patients with learning disabilities. The passports hold important information to make sure patients get the right care and receive appropriate communications. Health passports are widely used and understood by patients with learning disabilities and their families. NHS England is currently developing national guidance on the content and use of passports. It should consider DNACPR decisions as part of this review.

This recommendation is not new and was called for by the CQC in 2021. The evidence suggests that the issue around DNACPR documentation still exists, so we urge action in this area.

Changing the current DNACPR form

Doctors told us there is very little room on DNACPR forms to give more context for DNACPR decisions. This risks the reasons for DNACPR decisions and details of conversations with patients and families being documented poorly.

The lack of space can create a reductive approach to understanding people's needs and to accountability. Giving doctors space to only write a few words could give the impression that documenting a complex decision is unimportant. The reasons given for the DNACPR and notes from conversations are particularly important to a review of cases by the Ombudsman, but the lack of space on the form itself gives little room for accountability around decisions.

As well as increasing space, there is an opportunity to use the DNACPR form to clarify legal duties for doctors to consult patients, families and carers. Doctors have asked for more clarity on the legal framework behind DNACPRs. Rather than relying only on training to deliver this information, we recommend changes to all DNACPR forms to include legal duties to consult. Precedent exists for this in death certification.

5. Overarching recommendation

5.1 We call for all outstanding recommendations in CQC's 'Protect, respect, connect – decisions about living and dying well during COVID-19' to be implemented.

Our commitment

We will train all Ombudsman staff on disability awareness in our 2024 to 2025 Active Inclusion learning programme, including learning disability and neurodiversity. This should mean staff will be able to recognise when these characteristics arise as a factor in a complaint and better understand the lived experiences of individuals and families. We will continue to progress work to make our services more accessible to disabled people, older adults and people affected by issues in this report.

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